



CRS Parent Connection

Alabama Department of Rehabilitation Services



Volume 11, Number 2

Summer 2003

Meet Our Parent Consultants

More than three years ago, Patti Fassbender, who was the physical therapist treating my children, asked me if I would be interested in a part-time job



working for CRS. I couldn't imagine that there was a job made for me. I had not yet completed my degree in Early Childhood Special Education, I had three children with disabilities, and I couldn't work 40 hours a week. But, thankfully, I was wrong. There *was* a perfect job for me.

My name is Penny Strickland and I am the parent consultant for Mobile CRS. I have been working with CRS families for three years. I feel very fortunate to have this position because it not only allows me to help families, but it also enables me to learn more about area resources, our local school system, and legislation that impacts all children with special health care needs. I am proud to serve as the liaison for the local Parent Advisory Committee (PAC) and to represent CRS at the District Coordinating Council and Training Subcommittee meetings.

Although I have only been the parent consultant for three years, I have been associated with CRS for fourteen. My husband, Shannon, and I have three daughters. Payton is fifteen years old, and Lauren and Leann are ten. All three girls were born three months prematurely, and all three have cerebral palsy. Payton was referred to CRS when she was eleven months old. At that time, her doctor noticed that she was experiencing developmental delays in her gross motor and fine motor skills. She began receiving PT and OT services when she was twelve months old. She has had too many surgeries to mention and uses a power wheelchair for mobility. She is in the ninth grade, maintains a 3.75 GPA in advanced classes, and she insists that being left-handed is her only real disability. Payton has also dedicated more than 150 hours to community service through Project SUCCESS, a program that is sponsored by CRS and United Cerebral Palsy (UCP), and is very excited about participating in the CRS Teen Clinic.

Lauren and Leann have been a part of CRS since they were born the day after Christmas in 1992. They are in the fourth grade. Lauren attends regular classes for history and science but receives help in the resource room for math and

(Continued on page 5)

Inside.....

Statewide Resource Center.....
HIPAA Is Here.....
Smile Alabama.....
Youth News.....

P. 3
P. 3
P. 4
P. 5

Achieving Community-Based
Service Systems..... P. 6
Family Voices..... P. 8
Beach Mats a Milestone..... P. 9



CRS Parent Connection

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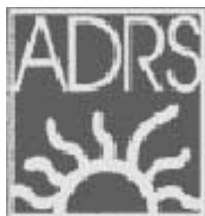
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Parent Connection is a complimentary Newsletter (published by Children's Rehabilitation Service) for families of children with special health care needs. The goal of this newsletter is to increase communication and share information about children with special health care needs and their families. The newsletter reflects a family-centered theme throughout and serves as a forum for family members to share information, thoughts, feelings, concerns, etc. Nothing printed or implied in this publication constitutes an endorsement by the Alabama Department of Rehabilitation Services.

This material is available in alternate formats upon request. Alternate formats include braille, large print or audio tape and may be obtained by calling the phone numbers listed above.

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From The Director's Chair



Hello, Everyone!

Spring is everywhere around us. It's so wonderful to see so many beautiful things coming to life again. Trees are filling out with new leaves and providing us with cool shady places to rest. Flowers and plants are blooming, creating a background of beautiful colors and sweet aromas that make us smile. Birds and animals are becoming active again, reminding us that life is always renewed. So many things to be thankful for and smile about!

Spring also gives us a chance to say thanks to mothers and fathers who provide love, care and support for the children and young people we are so blessed to serve at CRS. Mother's Day and Father's Day give us all a time to focus on moms and dads. However, I know that the children and young people we serve at CRS are loved, cared for and supported by many others as well.

Over the past few weeks, ADRS Commissioner Steve Shivers and I have been visiting CRS clinics across the state and talking to parents, children and youth, family members, CRS staff, doctors, therapists, and others. The purpose of our visits is simply to talk to families and CRS staff to find out how we are doing and how we can better serve and support children with special health care needs and their families. What has made such a huge impression on me during these visits is the unconditional love and support given to children by their parents, grandparents, family members and others – even in the face of difficult and trying circumstances and personal sacrifices.

It doesn't take a brilliant person to realize that love, support and care make a critical difference in the progress, development and lives of children and young people with special health care needs. We at CRS know that YOU, the caregivers, are essential in enabling us to provide quality

(Continued on page 4)



Statewide Resource Center

A grant from the Alabama Council for Developmental Disabilities (ACCD) has made possible the establishment of a statewide Developmental Disabilities Resource Center at the Comprehensive Health Education Center for Kids (C.H.E.C.K.) in the main lobby of Children's Hospital in Birmingham, Alabama. This resource center will provide information free of charge to all Alabama children with developmental disabilities and their families. A bibliography of materials has been compiled of the books, brochures and videotapes available for check-out. To receive a copy of the bibliography or to check out materials, contact the C.H.E.C.K. Center at 1-866-800-7259 or look for the bibliography of materials at their website, <http://check.chsys.org>.

Other informative websites:

- www.icdr.us was developed by the Interagency Committee on Disability Research to gather comments about research needs for Americans with disabilities. This web site will be a source for recommendations to the president and Congress on policy and priorities related to disability and rehabilitation research. Comments gathered will help ensure that federal research efforts meet the needs of the disability community.
- www.YesICanKids.gov was created by the White House Initiative on Educational Excellence for Hispanic Americans. Pablo the Eagle directs children to stories they can read and art work sent in by students from across the country. This site is available in both English and Spanish. Its parent site, www.YesICan.gov, has bilingual information to help parents navigate the education system from early childhood through college.

HIPAA IS HERE!



By now you have all been bombarded with privacy notices from insurance companies, pharmacies, doctor's offices and CRS. All this is in response to the new Federal Laws on the privacy of health information - **HIPAA**. By April 14, 2003 all health insurance plans and health care providers had to begin posting and offering to their clients a notice of how any health information about them would be used. The good news is that you will only be asked to sign for the Privacy Notice once.

Additional forms the staff of CRS, doctor's offices and hospitals will be continually asking you to sign are the **Authorization for Release of Information** forms. Most of the time a health care provider will have to have your signed permission to send health information to another provider, a school or other program. For some CRS clients, the families may be asked to sign 5-10 of the **Authorization for Release of Information** forms at one time. If you are presented with multiple release forms, please realize the CRS staff is trying to coordinate health services and the law requires your signed permission to do this.

If you have any questions about how CRS is dealing with HIPAA, please feel free to talk with any of the CRS staff or contact the Alabama Department of Rehabilitation Services Privacy Officer, Linda Jennings. Linda Jennings can be contacted at one of the following: P.O. Box 11586, 2129 E. South Blvd, Montgomery AL 36111-0586; (334) 281-8780; 1-800-441-7607; or ljennings@rehab.state.al.us.

(Continued from page 2)



Smile Alabama!

is the Alabama Medicaid Dental Program Outreach Initiative for children. The first goal of this initiative is to increase the number of dental providers. This is being done through recruitment of new providers, and assisting dentists in accepting new Medicaid patients. Today, Alabama has 30 percent fewer dentists statewide than the nation.

The second goal is education of Medicaid clients and the general public about the importance of preventive dental care and good oral health. Almost 70 percent of low-income children in Alabama did not visit a dentist last year. Dental-related illness causes low-income children to miss 12 times more school days than children from higher income families.

For more information, visit the Medicaid website at www.medicaid.state.al.us/Dental or ask your present dental provider about **Smile Alabama!**

services to these children and young people. So to you, the caregivers — the mothers and fathers, grandmothers and grandfathers, aunts and uncles, brothers and sisters, and others who provide care — the CRS staff and I would like to say a sincere **THANK YOU!**

Hey ... perhaps this spring we can celebrate another new beginning, the beginning of a day to recognize some very important and wonderful people, soooooo ...



Happy **CAREGIVER'S** *DAY!!*

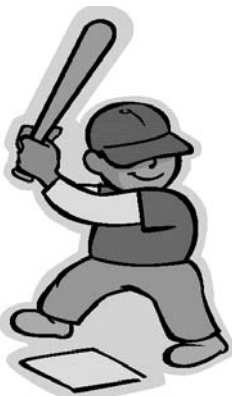
You deserve it! You make a difference!

Thank you!

Cary Boswell, Assistant Commissioner

Alabama Department of Rehabilitation Services

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Batter Up

If you are a baseball fan, you won't want to miss the Atlanta Braves baseball game in Atlanta, Georgia, June 26. It will be Exceptional Parent Disability Awareness Night.

Disability Awareness Night began last year with Exceptional Parent Magazine teaming up with the New York Yankees and Boston Red Sox. A pre-game ceremony was held at home plate to raise awareness of 54 million Americans who have a disability or special health care need and the efforts being made to improve their lives. Several Major League Baseball clubs have committed dates for Exceptional Parent Disability Awareness Night for the 2003 season.

YOUTH NEWS

I am Jennifer Thomas, the CRS Youth Consultant, and I am back to "YAC" about the great things that the Youth Advisory Committee (YAC) has been involved in. During January and February, the Youth Advisory Committee was very busy planning and organizing for the Alabama Transition Conference which was held in Auburn, Alabama, March 5-7, 2003. Information had to be gathered, the presentation had to be developed, and parts had to be assigned. However, this was not too big of a challenge for the YAC members! Jennifer Oveson, Brent Holland, Ryan Colburn and Roosevelt Wright, along with Mrs. Linda Graham and myself, came together and put on a great presentation titled *Youth Speak Out*. In this presentation, YAC members addressed parents, teachers, policymakers, health care providers and employers regarding various issues that they face as youth with disabilities. I was very proud of the participants, and I feel that they all did a fantastic job. We were even asked by Dr. Cary Boswell, Assistant Commissioner of the Department of Rehabilitation Services, to give our presentation again at other events.

Mrs. Linda Graham and I are in the process of planning summer activities for the Youth Advisory Committee. If anyone has any suggestions, please email Mrs. Linda Graham at lgraham@rehab.state.al.us. Also, I can be contacted at jthomas@rehab.state.al.us.

Thanks,
Jennifer Thomas, CRS Youth Consultant



(Continued from page 1)

English. She recently started wearing bifocals, and she has an Intrathecal Baclofen (ITB) pump implant that relieves her spasticity. She also uses a power wheelchair for mobility. She is a true joy to all that meet her. Leann attends regular classes, receives no special education services, and has been a Super Star Student award winner every year since kindergarten. When she was twenty months old, Leann had surgery to release her heel cords and adductors. She began walking independently when she was two. Seeing her walk for the first time was a joyous occasion for our family, and CRS played a big part in making it happen.

It is only natural for me to want to work at CRS because it is a wonderful organization with many caring employees. They have provided unlimited information and support to my family as well as financial assistance for durable medical equipment, surgeries, prescriptions and miscellaneous supplies that were not covered by insurance. And they cheered for me when I won the big red van from Regis and Kathie Lee in 2000. I am delighted to be a part of a team that dedicates itself to helping families who have children with disabilities and special health care needs.

Please feel free to visit me anytime you are in the Mobile area. I can also be contacted by phone or email.

Penny Strickland, Mobile CRS
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Please add me to your newsletter mailing list.

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Achieving Community-Based Service Systems for Children and Youth with Special Health Care Needs and Their Families

By: Lynda Honberg
Maternal and Child Health Bureau
Department of Health and Human Services

When my daughter Sarah was born ten years ago, I often struggled with what to call her condition. Crouzon's Syndrome was far too clinical and cranio-facial condition or facial difference just didn't roll off my tongue very easily. And I absolutely hated the word birth defect—because she is definitely **not** defective in any way. My dilemma was solved when I heard the phrase “children with special health care needs” because Sarah is **so** special and she does have many health care needs.

Children with special health care needs are those who have or who are at increased risk for a chronic physical, developmental, behavioral or emotional condition, and who also require health and related services of a type or amount beyond that required by children generally.

This definition was developed under the leadership of the federal Maternal and Child Health Bureau and has now been accepted by child health experts nationwide, including the American Academy of Pediatrics. In the past, categorizing children by their diagnosis led to a proliferation of disease specific programs and a fragmentation of services. An assumption was also made that the need for services was limited to children with disabilities that restricted their daily functioning or activity. This new definition recognizes that there is a broader group of children who have ongoing needs for health services.

Despite the vast array of diagnoses and conditions, children with special health care needs and their families all share the same need for a comprehensive system of care that allows them to live, to be educated, to play and to build relationships in their community. It is estimated that 13percent of our nation's children have a special health care need. While the nature, scope and intensity of services varies, adopting this definition shifts the focus to developing systems of care that meet

the needs of **all** these children, regardless of the specific diagnosis or category.

Seven years after I heard this phrase, “children with special health care needs,” I accepted a position with the Maternal and Child Health Bureau (MCHB)/ Department of Health and Human Services. As I frequently speak with families of children with special health care needs across the country, including families referred to me by AboutFace, the same issues are universally brought up. Families want to have access to a physician who will be compassionate and provide coordinated, ongoing and comprehensive care. They are tired of trying to organize the vast array of services their child needs, especially coordinating school and medical services. Families often feel their voices and concerns are not heard, and they are not always satisfied with the care their child is receiving. Not enough is being done to assure their son or daughter can transition to adulthood. And more than anything, families want health insurance that pays for the services their child needs and includes their child's providers.

In response to this need, the Social Security Act was amended in 1989 and mandated Title V Maternal and Child Health Programs for Children with Special Health Care Needs to “facilitate the development of community-based systems of services for such children and their families.” This focus on improving service systems for these children is also reflected in both Healthy People 2000 and Healthy People 2010, the nationwide agenda developed by the U.S. Surgeon General to improve the health of all the people in the United States. Healthy People 2010 includes an objective to “increase in the proportion of territories and states that have service systems for children with special health care needs.”

Under the leadership of the MCHB, six performance outcomes were developed as a way to measure progress in meeting the Healthy People objective and our mandate under the Social Security Act. These outcomes—our promises for



(Continued on page 7)

(Continued from page 6)

all children with special health care needs—are as follows:

1. Families of children with special health care needs will partner in decision-making at all levels and will be satisfied with the services they receive.
2. Children with special health care needs will receive coordinated, ongoing, comprehensive care within a medical home.
3. Families of children with special health care needs will have adequate private and/or public insurance to pay for the services they need.
4. All children will be screened continuously for special health care needs.
5. Community-based service systems will be organized so families can use them easily.
6. Youth with special health care needs will receive the services necessary to make transitions to all aspects of adult life, including adult health care, work and independence.

Our goal to achieve community-based systems of care is also part of the President's New Freedom Initiative, a major activity across federal agencies to increase community integration for people of all ages with disabilities. In *Delivering on the Promise*, a report to implement this initiative, the MCHB was given the responsibility of developing and implementing a plan to achieve appropriate community-based systems for children and youth with special health care needs and their families. We are in the process of working with many partners—families; providers; health insurers; public agencies at the federal, state and local levels; businesses, and voluntary organizations to develop practical action steps and strategies to develop this plan.

Another exciting development is the completion of the first National Survey on Children with Special Health Care Needs. The survey interviewed 750 families with a child with special health care needs in each state and the District of Columbia. For the first time, we are able to assess the prevalence of special health care needs among children and explore the extent to which these children have medical homes, adequate health insurance and access to needed services. Results of the survey, along with the products of other initiatives, will provide us with a national database to

perform needs assessments, measure quality of care, and promote and implement the services needed by children with special health care needs. For more up to date information, go to the MCHB website at www.mchb.gov.

I have worked in both the private and public sector, and I have to say in all honesty, I have never been part of a more strategic, forward-thinking program. Yes, our goals are ambitious, and given budget and resource limitations, we face huge obstacles. But I am convinced by 2010, we will make progress on the Surgeon General's objective to assure that all children with special health care needs have access to the system of care they deserve.

I will keep you abreast of our progress in the years to come. If you are interested in getting more information or about specific initiatives in your state, feel free to email me at LHonberg@hrsa.gov

See Lynda's bio on page 9.



FAMILY VOICES

Bright Futures for Families



Bright Futures is a vision and a philosophy of children's health care. It offers a practical approach to good health for children from birth through adolescence. Bright Futures is dedicated to the principle that every child deserves to be as healthy as possible and that the best health care involves a trusting relationship between a child and family, a health professional, and their community. Bright Futures was initiated and funded by the U.S. Department of Health and Human Services, Maternal and Child Health Bureau (MCHB). Family Voices, with support from MCHB, encourages partnerships and works to develop information for families about raising healthy children, including children with special health care needs.



The Bright Futures Family Pocket Guide was developed so that families will have access to a wealth of information important to ensuring children's health. It follows the Bright Futures Guidelines for Health Supervision available for use by professionals. The Pocket Guide is a quick reference for families highlighting important child health topics. It is divided into four age groups: Infancy (birth-11 months), Early Childhood (1-4 years), Middle Childhood (5-10 years) and Adolescence (11-21 years). Each of these sections is divided further into two sections: *Thinking Ahead*, which offers information about what to expect as your child grows and develops, and *Your Child At*, which covers areas relating to your child's physical and

emotional health. Each visit with a health care provider is an opportunity to work as a team and to think about your child's needs and how to help him or her. You should also leave with information and guidance to help you as a parent. However, sometimes you might not be sure what to expect or what questions to ask. The Pocket Guide gives you information about what procedures may be expected at a well-visit for each age and things you can think about before you go for the visit.



The Pocket Guide also includes resources such as an immunization schedule and a place to record immunization records for up to three children, a place for you to record important phone numbers, and ideas for healthy snacks, safe use of the Internet by children and home safety. There are many resources listed for families, and a special section of resources for families with children with special needs.



If you are interested in obtaining a copy of the Bright Futures Family Pocket Guide, ask your CRS Care Coordinator or your local parent consultant, or you can call 1-800 ASK HRSA for a free copy. Also, check out www.brightfuturesforfamilies.org for more information. Family Voices has more Bright Futures information on our website, www.familyvoices.org, and we will be featuring other items of interest in upcoming issues of the Parent Connection.





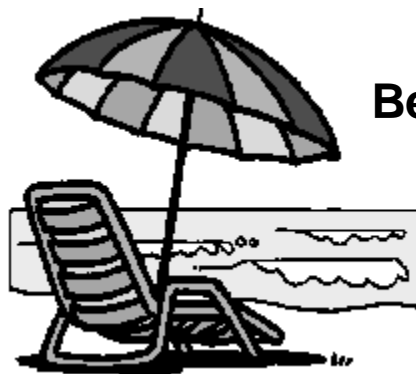
Writer Biography Lynda Honberg

Lynda Honberg is the proud mother of Sarah, a very special girl, who despite many obstacles and numerous surgeries is now an active eleven year old. Lynda has over 20 years experience in managed care in both the private and public sectors and is recognized as an expert on the issues of caring for special populations in managed care. In her current position with the Maternal and Child Health Bureau (MCHB), Ms. Honberg is responsible for a \$3.5 million initiative to assure that children with special health care needs have adequate insurance. Lynda also works closely with AboutFace on the national and local level.

Previously Lynda was the director of Managed Care for the HIV/AIDS Bureau where she developed managed care training and technical assistance programs for Ryan White C.A.R.E. Act funded programs. For eight years, Lynda was the director of Operations for the George Washington University Health Plan of Washington, D.C. Her other experiences include developing an IPA for Blue Cross-Blue Shield of the National Capital Area, advising employers and unions on health benefit packages, and managing grants to develop and finance HMOs for the Office of Health Maintenance Organizations.

Lynda has a masters degree in health services administration from the University of Michigan School of Public Health and a bachelors degree in health education from State University of New York at Cortland.

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Beach Mats a Milestone

By Bart Brophy
Access Disability Action Center
Hilton Head Island, South Carolina

What a great moment it was for Hilton Head Island when the beach mats were installed, opening an opportunity for all people to access a gift from our Creator—the beach. The spirit of the Americans with Disabilities Act lives on. The Mobi-mat appears to be the perfect product for tourists and residents who use wheelchairs, walk deliberately, push strollers, have children with disabilities, and much more. Already, we have many people using it. We are arranging to have wheelchair tennis players from all over the world (here for a tournament at Van Der Meer Tennis Center) try our beaches with ease and zero aggravation. We have heard encouraging words from the governor's office and disability groups worldwide. We truly feel this was a historical breakthrough in understanding.

The entire business community here now can add this to the list of our island's great features and benefit from its value. We commend the town of Hilton Head Island for having the courage to move into a leadership role worldwide on a misunderstood issue. The island was one-dimensional from our perspective until now. Those folks we interact with on the beach gain from our unique experiences and perspectives on life. We hope to get back into committee meetings to discuss other products and other beaches.

P


arenting Today



Building Strong Character

1. **Be a good example.** Face it, human beings learn primarily through modeling. In fact, you can't avoid being an example to your children, whether good or bad. Being a good example, then, is probably your most important job.
2. **Develop an ear and an eye for what your children are absorbing.** Books, songs, TV, the Internet and films are continually delivering messages—moral and immoral—to our children. As parents we must control the flow of ideas and images that are influencing our children.
3. **Get deeply involved in your child's school life.** Helping our children become good students is another way of helping them acquire the habits that build strong character.
4. **Make a big deal out of the family meal.** Manners, rules and values are subtly absorbed over the dinner table. Family mealtime should communicate and sustain ideals that children will draw on throughout their lives.
5. **Do not reduce character education to words alone.** We gain virtue through practice. Parents should help children by promoting moral action through self-discipline, good work habits, kind and considerate behavior to others, and community service. The bottom line in character development is behavior—their behavior and yours.

Source: Kevin Ryan's "Ten Commandments for Parents," Appendix I in *Building Character in Schools*; Ryan, K. and Bohlin, K.E.; Jossey-Bass, 1999



De-stress Your Kid

1. Accept your child's limitations. A child with the capacity to get only B's or to perform only average in athletics or music can become guilt-ridden if he thinks he's done his best but let you down.
2. Don't compare your child's abilities, talents or looks with those of other children.
3. Celebrate your child's accomplishments; go to school plays and games, post schoolwork, etc.
4. Encourage your child to express his feelings: tell him it's OK to feel sad and to cry. Take time to listen without giving advice or passing judgment.
5. Spend some one-on-one time with your child every day.
6. Show your child that you respect people and that you respect life. Help him learn to respect others.
7. Expect some rebellion and remember, "This, too, shall pass." Don't make a big issue out of small things that bother you.
8. Be honest when answering questions about delicate issues such as sex, divorce or death.
9. Restrict and monitor TV and movie viewing.
10. Sympathize with your child when he experiences a loss.
11. Set a good example: show your child that when you're depressed, you work out your frustrations by talking to friends, exercising, praying or enjoying something funny, etc.
12. Consult a health professional if you think your child is having problems neither he nor you can handle.

Reprinted from "Health Watch"; State Employees' Insurance Board; Montgomery, AL; March 2003

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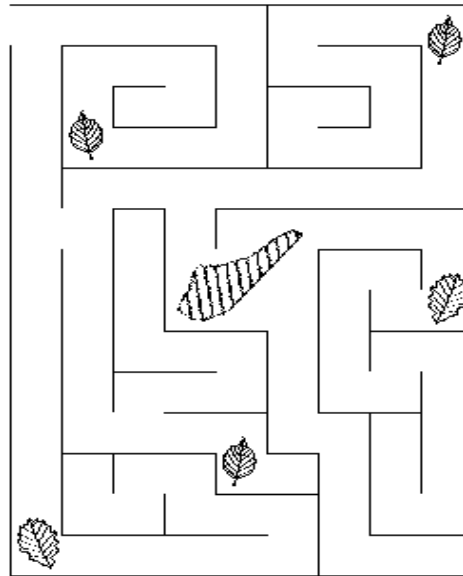
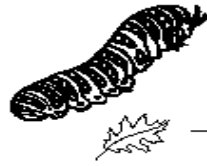
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Help The Caterpillar

Can you help the caterpillar through the maze so that she can become a butterfly?



Bry-Bach Manor 2000

Art Fun

Enjoy art with your child. Draw a picture, cut paper shape pictures, make things with yarn, paper cups, fabric, twigs, feathers, etc. As you work together, talk about what you are making. Tell a story about your art. Encourage your child to relate his thoughts as he works to create something wonderful.

For fun try creating with the playdough recipe listed below.

No-Cook Playdough

1 cup cold water

1 cup salt

2 teaspoons oil

3 cups flour

2 tablespoons cornstarch

food coloring (optional)

Mix water, salt and oil. Gradually add flour and cornstarch. Mix and knead.

Divide and add food coloring to each part. Or use markers to draw on white dough.

Store playdough in zip-lock bags.

**CRS Parent Connection**

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ut What's Ahead

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|------------------|--|
| Jun. 11-13, 2003 | Alabama Association of Persons in Supported Employment Conference; Adam's Mark Hotel; Mobile, AL; Contact: Byron White, 1-800-441-7607 or Lisa Alford, (205) 554-1300 |
| Jun. 20, 2003 | Estate Planning Workshop for Individuals w/ Disabilities & Their Families; Houston County Extension Office; Dothan, AL; Contact: (334) 420-0688 |
| Jun. 27-28, 2003 | ADBMA Statewide Meeting & Helen Keller Festival; Sheffield Holiday Inn; Sheffield, AL; Contact: Veronica Tuck, (256) 761-3314, Email: vtuck@aidb.state.al.us |
| Aug. 17, 2003 | Sharon's Ride Run Walk for Epilepsy; Daphne High School; Daphne, AL; Contact: sharonforepilepsy.org |
| Sep. 11-15, 2003 | American Therapeutic Recreation Association Conference; Sheraton Atlanta Hotel; Atlanta, GA; Contact: www.atra-tr.org/futureconference |
| Sep. 18-22, 2003 | World Congress & Expo on Disabilities; Orlando, FL; Contact: www.wcdexpo.com |
| Nov. 19-21, 2003 | Early Intervention Conference 2003 Alabama; VonBraun Center; Huntsville, AL; Contact: Jeri Hughes, (205) 823-9226, JBH50@aol.com |